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AUTHOR Stoecklin, Vicki L.
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ABSTRACT

This theme issue provides an overview of how parents and professionals can be involved in advocacy efforts for children with disabilities, ages 3 and older. The guide begins with a definition of advocacy and a discussion of parents' and professionals' roles as advocates. It outlines legal rights, specific parental rights provided by the Individuals with Disabilities Education Act, suggestions to parents in exercising parental rights, performance standards relating to parent involvement with Head Start programs, and a description of the special education system and effective ways to handle the system. Appendices provide the School Assertiveness Inventory, an "ERIC Digest" on rights and responsibilities of parents of children with disabilities, a list of parent training centers, qualities of a good advocate, advocacy strategies, and updates on advocacy activities in six states. Seven references and a bibliography of seven items are provided. (JDD)

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ADVOCATING FOR YOUNG CHILDREN WITH DISABILITIES

INTRODUCTION

The purpose of this Quarterly Resource is to provide an overview of how parents and professionals can be involved in advocacy efforts for children ages three and older. This document is not intended to duplicate other resources currently available, but is based on my professional and personal experience as a parent of a child with a disability and as an advocate for other children. I hope that you will use it as a springboard to locate other materials.

Vicki L. Stoecklin
Great Lakes Resource Access Project
University of Illinois

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ADVOCATING FOR YOUNG CHILDREN WITH DISABILITIES

LET'S DEFINE ADVOCACY

An advocate can best be described as a person who speaks on behalf of or in partnership with someone else such as a child or a parent in order to procure needed services. Within the context of this document, we will be discussing the term "advocate" in relationship to finding appropriate services for young children with disabilities and their families.

The basic characteristics of a good advocate include personal characteristics that may be currently possessed or acquired by a variety of different people concerned with the child. According to Cutler (1981), these basic characteristics include:

1. Great concern for the child's best interests.

2. Commitment to the child's welfare and to being the child's advocate.

3. Knowledge of the present needs of the child or the ability to recognize those needs.

4. Assertiveness in persistently pointing out the child's needs to the people responsible for meeting those needs.

5. Ability to work with others (e.g., professional, para-professionals, other parents and advocates) to develop appropriate and beneficial educational goals and plans for the child.

6. Ability to find and use information, allies, and resources to put the needed educational plans to work.

WHO SHOULD ADVOCATE?

Parents

There are important reasons for parents to recognize their ability to act as advocates for their children. The first and foremost reason is that parents know their children better than anyone else. Parents can assist the school in understanding their children and providing services within a family-centered context. Long-term research has clearly shown that active parent involvement in pre-school activities can help children better reach their potential. Another reason for parents to be involved is that children are too young to speak for themselves and therefore depend on parents to speak on their behalf. Parents want what is best for their children.

Parents who are actively involved in their child's education increase their capacity to engage in meaningful activities with their children as prime educators. Parent advocacy can also offer the opportunity for parents to locate and utilize community supports and resources to their advantage. A greater ability to meet family needs can strengthen family pride, dignity and respect.

Some parents may not be able to advocate for their child for a variety of legitimate reasons. Parenting a child with a disability can be a stressful and time consuming job. Some parents may not have enough time or emotional strength left to be as assertive as necessary in advocating for their child. Some parents may not have the time to learn new skills. Other parents may be lacking the additional supports that allow their family to be involved in outside activities such as monies for child care and/or transportation. Parents from cultures other than those from European origins may have difficulties operating in a culture whose norms are very different than their own.

In fact, differences in cultural values and orientations between Anglo-European and other ethnic/cultural groups may create a situation where parents need to receive additional training and information on how to be bi-cultural and how to operate within the dominant culture before learning skills to be an effective advocate.

For example, some cultures are based upon values where group welfare and the acceptance of fate is necessary. Families from such cultures may have unique difficulties operating within a value system that places individual needs first and asks the family at times to do what they may feel is very unaccepting of fate, such as asking for individualized services. In addition, some cultures do not value asking for services in direct and assertive ways. It is important to make sure that parents of all cultures receive the support necessary to help them become stronger as a family unit.

Comparison of Common Values

Anglo-European	Other Ethnocultural Groups
Mastery over nature	Harmony with nature
Personal control over the environment	Fate
Doing-Activity	Being
Time dominates	Personal interaction dominates
Human Quality	Hierarchy/rank/status
Individualism/privacy	Group welfare
Youth	Elders
Self-help	Birthright inheritance
Competition	Cooperation

Future orientation	Past or present orientation
Informality	Formality
Directness/openness/honesty	Indirectness/ritual/"face"
Practicality/efficiency	Idealism
Materialism	Spiritualism

Source: Adapted from Benjamin, et al, 1991.

Resources for Parents

Other more experienced parents can also be seen as a resource for newer parents who are beginning to acquire skills as advocates. Parent Training Centers funded throughout the United States often have a diverse group of parent mentors who can assist families in negotiating the special education maze. These training centers also provide additional resources to parents and provide parent-to-parent training on families' rights under federal and state laws.

Another excellent resource for parents are specific disability organizations such as your local chapter for United Cerebral Palsy, or The Association for Retarded Citizens. These local organizations can provide information about specific disabilities and parental rights. In addition, many groups provide support groups for parents.

Professionals

Professionals are another group of interested adults who may be able to serve as an advocates in getting services for young children and their families. Professionals who would like to involve parents as active partners in advocacy efforts should make the following assumptions:

1. Parenting a child with a disability is a challenging job; it can be time consuming, demanding, stressful and never ending. Supportive relationships can help to reduce the stress.

2. Child rearing is a unique endeavor. Parents will have different goals for their children and different ways of achieving these goals. There are many right ways to parent.

3. Most parents want to be good parents and will work to the best of their abilities to fulfill those responsibilities. They can bring a wealth of information to professionals about a child.

4. Parents are unique individuals and therefore possess varying degrees of skills and knowledge. Parents will interpret their parenting role in a variety of ways.

No matter what our jobs are in working with young children, advocacy must be part of our professional responsibility. Parents can be supported in their additional responsibilities of advocacy when others such as professionals, especially those in administrative positions, share in their efforts.

RIGHTS UNDER THE LAW

Acquisition of knowledge can be the first step in developing skills necessary to advocate. Requirements at both the federal and state level entitle a child with a disability to receive a free, appropriate public education. State and federal laws and regulations guarantee that a child with a disability has equal opportunity to benefit from public instruction. Knowledge of laws can prepare families and professionals to become stronger advocates for children and assist both parties in understanding the entire service delivery system.

Legal rights are entitlements and not favors. Having rights under the law means that families of young children cannot legally be denied services. School systems are obligated to take the rights of children with disabilities very seriously. The following laws protect the rights of children with disabilities and their families. Call your State Education Agency contact person or your Resource Access Project, if you are a Head Start program, to find out how to receive a copy of these laws.

Federal Laws

- The Individuals with Disabilities Education Act (IDEA), P.L. 101-476, formerly the Education for All Handicapped Children Act, P.L. 94-142, 34 Code of Federal Regulations, Part 300 (the implementing regulations for IDEA)
- Section 504 of the Rehabilitation Act of 1973
- Title III of the Americans with Disabilities Act[1]
- Title VI of the Civil Rights Act of 1964
- Title IX of the Education Amendments of 1972
- Family Education Rights and Privacy Act (FERPA)
- Education Department General Administrative Regulations (EDGAR)) (CFR 76)

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[1] Title III of the Americans with Disabilities Act of 1990 (ADA) prohibits discrimination against young children with disabilities in Head Start programs and day care facilities. For specific information on the ADA and its relevance to preschool, day care or Head Start programs see the Great Lakes RAP's **Quarterly Resource,** 7(3), 1992-3 (Clarkson, 1992) and **Caring for Children with Special Needs: The Americans with Disabilities Act and Child Care**, (Child Care Law Center, 1993).

State Specific Educational Codes and Rules

Illinois:

The School Code, Article 14
23 Illinois Administrative Code 226 (implementing regulation School Code, Article 14)
23 Illinois Administrative Code 226 Part 375 (student records)

Indiana:

Title 511 - Indiana State Board of Education
Article 7, Rules 3-16, Special Education Rules

Michigan:

Section 1701 and 1703, Act #451 of the Public Acts of 1976, Michigan Compiled Laws.
Revised Administrative Rules for Special Education, August 17, 1990

Minnesota:

Minnesota Statutes 120.17
Minnesota State Board of Education, Special Education Chapter 3525

Ohio:

Rules for the Education of Preschool Children with Disabilities Served by Public Schools and County Boards of Mental Retardation and Developmental Disabilities, Chapter 3301-31-01 to 3301-31-05.

Amended Substitute House Bill Number 248.

Wisconsin:

S. 51.44 Wisconsin Statutes
Chapter HSS 90, Wisconsin Administrative Code
Sub Chapter V of Chapter 115, Wisconsin Statutes
PI - II, Wisconsin Administrative Code

Head Start Performance Standards on Services For Children With Disabilities (45-CFR 1308)

PERFORMANCE STANDARDS

Subpart G - Parent Involvement Performance Standards

§1308.21 Parent participation and transition of children into Head Start and from Head Start to public school.

(a) In addition to the many references to working with parents throughout these standards, the staff must carry out the following tasks:

(1) Support parents of children with disabilities entering from infant/ toddler programs.

(2) Provide information to parents on how to foster the development of their child with disabilities.

(3) Provide opportunities for parents to observe large group, small group and individual activities described in their child's IEP.

(4) Provide follow-up assistance and activities to reinforce program activities at home.

(5) Refer parents to groups of parents of children with similar disabilities who can provide helpful peer support.

(6) Inform parents of their rights under IDEA.

(7) Inform parents of resources which may be available to them from the Supplemental Security Income (SSI) Program, the Early and Periodic Screening, Diagnosis and

GUIDANCE

(a) Grantees should help parents understand the value of special early assistance for a child with a disability and reassure those parents who may fear that if their child receives special education services the child may always need them. This is not the experience in Head Start and most other preschool programs where the majority of children no longer receive special education after the preschool years. The disabilities coordinator needs to help parents understand that their active participation is of great importance in helping their children overcome or lessen the effects of disabilities and develop to their full potential.

The disabilities coordinator should help program staff deal realistically with parents of children who have unfamiliar disabilities by providing the needed information, training and contact with consultants or specialized agencies. The coordinator should ensure that staff carrying out family needs assessment or home visits do not overlook possible disabilities among younger siblings who should be referred for early evaluation and preventive actions.

PERFORMANCE STANDARDS	GUIDANCE
Treatment (EPSDT) Program and other sources and assist them with initial efforts to access such resources. (8) Identify needs (caused by the disability) of siblings and other family members. (9) Provide information in order to prevent disabilities among younger siblings. (10) Build parent confidence, skill and knowledge in accessing resources and advocating to meet the special needs of their children. (b) Grantees must plan to assist parents in the transition of children from Head Start to public school or other placement, beginning early in the program year. (c) Head Start grantees, in cooperation with the child's parents, must notify the school of the child's planned enrollment prior to the date of enrollment.	(b) (c) As most Head Start children will move into the public school system, disabilities coordinators need to work with the Head Start staff for early and ongoing activities designed to minimize discontinuity and stress for children and families as they move into a different system. As the ongoing advocates, parents will need to be informed and confident in communicating with school personnel and staff of social service and medical agencies. Disabilities coordinators need to ensure that the Head Start program: •Provides information services available from LEAs and other sources of services parents will have to access on their own, such as dental treatment; •Informs parents of the differences between the two systems in role, staffing patterns, schedules, and focus; •Provides opportunities for mutual visits by staff to one another's facilities to help plan appropriate placement; •Familiarizes parents and staff of the receiving program's characteristics and expectations; •Provides early and mutually planned transfer of records with parent consent at times convenient for both system; •Provides information on services available under the Individuals with Disabilities Education Act, the federally-funded parent training centers and provisions for parent involvement and due process; and •Provides opportunities for parents to confer with staff to express their ideas and needs so they have experience in participating in IEP and other conferences in an active, confident manner. Role playing has been found helpful.

PERFORMANCE STANDARDS

GUIDANCE

It is strongly recommended that programs develop activities for smooth transition into Head Start from Part H infant/toddler programs funded under IDEA and from Head Start to kindergarten or other placement. In order to be effective, such plans must be developed jointly. They are advantageous for the children, parents, Part H programs, Head Start and LEAs. ACYF has developed materials useful for transition. American Indian programs whose children move into several systems, such as Bureau of Indian Affairs schools and public schools, need to prepare children and families in advance for the new situation. Plans should be used as working documents and reviewed for annual update, so that the foundation laid in Head Start is maintained and strengthened.

THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT

The Individuals with Disabilities Education Act (IDEA) is the most comprehensive legislation in outlining parental rights in seeking service for children with disabilities, ages 3-21. Basic parental rights during this process include (ERIC Clearinghouse on Handicapped and Gifted Children, 1989):

1. The right to a free, appropriate public education for the child.

2. The right to be notified whenever the school wishes to evaluate or change the educational placement of the child.

3. The right to initiate an evaluation of the child to determine if they are eligible for special education services.

4. The right to informed consent. Parental consent must be given in writing for evaluation and placement of the child.

5. The right to request a re-evaluation of the child if the parent feels that the educational placement of the child is no longer appropriate.

6. The right to obtain an independent evaluation of the child if the parent disagrees with the school's evaluation.

7. The right to have the child tested in the language he or she knows best.

8. The right for parental review of all the child's educational records.

9. The right to be informed of parental rights by the school.

10. The right to participate in the development of the child's individualized education program (IEP).

11. The right for the child to be placed in the least restrictive environment. In other words, the child should be educated in the most normal school setting possible.

12. The right to request a due process hearing if parental differences with the school district cannot be resolved informally.

Suggestions for Parents

In exercising parental rights under IDEA, there are many ways parents can carry out their responsibilities. Some of the following suggestions may be helpful:

1. Collect and read as much information as you can about the child's particular disability. The National Information Center for Children and Youth with Disabilities (NICHCY, 1-800-695-0285) can provide specific information about disabilities and a directory of other organizations, that includes disability specific organizations in your state. Resource Access Projects (RAPs) can also assist in locating materials in their libraries for Head Start.

2. Collect and read information about parental rights under the law. Parent Training Centers, specific disability organizations, early intervention clearinghouses, the State Education Agency in your state, RAPs and NICHCY will be able to provide resources.

3. Work to develop a relationship with the public school. Share information about the child and your family. Get to know the school personnel on a personal basis.

4. Come prepared to multi-disciplinary team meetings regarding the child. Observe and write down your concerns about the child's behavior. Make a list of your questions and concerns. Coordinate with your child's current service providers to collect as much information as possible.

5. In preparing for the Individualized Education Program (IEP) meeting, prepare a list of goals that you have for the child and the entire family.

6. Keep organized records. Be sure to write down important information. Keep copies of all information regarding the child in a special folder.

7. Ask clarification of any aspects of the evaluation and educational process that is not clear. Parents should never sign something they do not understand.

Parent Training Centers and the resources in the Appendix of this **Quarterly Resource** will be useful in training parents about their rights and how to better prepare themselves as advocates.

UNDERSTANDING THE SPECIAL EDUCATION SYSTEM

Most special education services provided under IDEA will be administered by school systems. Federal monies available to local school districts are allocated by the number of children identified as receiving special education services on December 1st. Each district decides how these federal monies will be used based on their state's education laws and their state education agency's plan and priorities. In addition, local school districts have access to state and local dollars for special education services. The amounts vary from location to location.

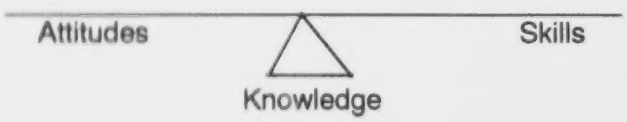
A school system is a bureaucracy and as such could be considered very conservative. Bureaucracies are not noted for their flexibility or desire to change. An effective advocate will understand the basic operation of the school system and know how to best approach this system in getting services for the child.

Like all bureaucracies, the school system has a hierarchial structure. Everyone in it works directly under someone else. Some school districts will administer their own special education services; other districts will band together to purchase services from agencies known as special education co-operatives. A call to your local district superintendent can clarify how special education services are administered and who to contact regarding questions and concerns about early childhood services. Parent Training Centers can also be helpful in obtaining information.

Depending on how the services are administered, responsibility for special education services is assigned differently in each district. Regardless of administrative structure, you can assume that the person who has the ultimate authority is the district superintendent. The superintendent is hired by the school board, which is elected by local voters. When systems may be resistant to change, strong advocates and community pressure can influence local special education services and policies.

EFFECTIVE WAYS TO HANDLE THE SYSTEM

Being effective as an advocate requires knowledge, skills, and attitudes that are all equally important in negotiating the special education maze. In fact, the inter-relationship of these facets can best be visualized as a see-saw. All parts are inter-dependent and necessary to the functioning of the whole. This concept can be visualized as:



Knowledge is the fulcrum or base of all actions. Each part is equally important, yet they must all be used together at the same time. Specific items that make up each part are:

Attitudes	Knowledge	Skills
Willingness to learn	Rights of parents	Assertiveness
Persistence	Rights of child	Positive communication
Consistency	Specific disability	Organized record-keeping
Self-worth	Child's needs	Listening skills
	System operation	

Knowing how to communicate in an assertive way is an important skill basic to effective advocacy. Being assertive means being able to stand up for yourself without violating the rights of others. Being assertive is very different from being aggressive where you stand up for your rights in a way that is demanding, demeaning and/or violates the rights of others. Being assertive means communicating your needs and beliefs in a positive way.

In order to present your case in an assertive way, you must develop a belief in yourself and your capabilities. It will take some practice to listen carefully to others and to state your point of view firmly, directly, and with respect. Parent Training Centers should be viewed as an excellent resource in finding ways to increase parents' ability to communicate in an assertive manner. The School Assertiveness Inventory in the Appendix may assist staff members in assessing their own assertiveness.

Another skill of a good advocate is the ability to collaborate with school personnel for improved services for the child. Collaboration means an openness to sharing ideas, where differences are expected and respected. In remaining open to suggestions, you may find it in the best interests of the child to compromise. This is called positive and successful negotiation. Effective collaborations will weigh all informed options prior to making final decisions.

WHEN MINDS DON'T MEET

We live in a less than perfect world. Sometimes, as advocates we cannot successfully achieve what we feel is right for the child. Try to resolve your differences with the school district superintendent or special education director at the local level. Talk to local school board members if you are unable to reach a satisfactory resolution. Contact your state education agency. They will be able to advise what steps you may take next. The SEA can also inform you about the complaint resolution process available to assist you in resolving differences. Many districts use a mediator, or outside "third party," to help find a mutually agreed upon resolution. This conflict resolution system is not intended to replace your rights to due process. In cases where disagreements on any matter related to the provision of a free, appropriate public education cannot be resolved

at the local level, parents have the right to proceed to a "due process hearing." IDEA sets forth minimum criteria that states must follow in due process hearings. There may be additional state laws that set forth requirements on rights, governance of hearings, and logistics.

Your state education agency's special education personnel, Parent Training Centers and RAP will be able to provide you with information about how the state handles due process hearings. Many states publish booklets on parents' rights that include such information. In addition, each school district and special education cooperative must have approved special education policies and procedures. You should be able to obtain copies of your school district's policies and procedures through your local director of special education or the district superintendent.

SUMMARY

It is important for Head Start staff to assist parents and advocates to develop the assertiveness skills, and contacts necessary to obtain services their children need. Parents and professionals need to collaborate in establishing consistent policies and procedures to create a service delivery system that is more open to all children and families. We will more fully realize our strengths as a nation, when all children have the opportunity to achieve their maximum potential. Advocacy can best be summarized as assisting and supporting someone to reach their maximum potential.

> "Whenever I approach a child, his presence inspires two feelings in me:
> Affection for what he is now and respect for what he may one day become."
>
> Louis Pasteur.

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APPENDIX A
SCHOOL ASSERTIVENESS INVENTORY

Do you feel and act assertively in school situations? To find out circle the answers to the following questions. Please rate your responses from Very Characteristic (YES) being 5 to Not Characteristic (NO) being 1.

1.	I feel comfortable and at ease when I am at a conference with school personnel.	5	4	3	2	1
2.	I ask questions if I don't understand a term or procedure.	5	4	3	2	1
3.	I make direct requests for services or options that I feel are necessary.	5	4	3	2	1
4.	I refuse to accept plans or suggestions that I feel are inappropriate or inadequate for the child.	5	4	3	2	1
5.	I tell others at a meeting if I feel angry or disappointed.	5	4	3	2	1
6.	I feel that children are entitled to the special services that meet his or her needs.	5	4	3	2	1
7.	I feel that my opinions are respected by school personnel.	5	4	3	2	1
8.	I tell others at a meeting if I am pleased with or appreciate their efforts.	5	4	3	2	1
9.	I feel that I look and act self-confident during conferences and in school situations.	5	4	3	2	1
10.	I feel that conferences result in plans that are appropriate for children's needs.	5	4	3	2	1

Prepared by Geraldine Markel, Ann Arbor, Michigan, 1979. Source: Parent Project (1989).

ERIC Clearinghouse on Handicapped and Gifted Children
THE COUNCIL FOR EXCEPTIONAL CHILDREN
1920 Association Drive • Reston, VA 22091-1589
FAX (703) 264-9494

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APPENDIX B
RIGHTS AND RESPONSIBILITIES

1989

RIGHTS AND RESPONSIBILITIES OF PARENTS OF CHILDREN WITH HANDICAPS

What are your rights, as a parent, in the special education process?

Public Law 94-142 clearly defined the rights of children with handicaps and their parents. A fundamental provision of the law is the right of parents to participate in the educational decision-making process. This includes the right to

- **A free appropriate public education for your child.** *Free* means at no cost to you as parents. *Appropriate* means meeting the unique educational needs of your child.
- **Be notified whenever the school wishes to evaluate your child,** wants to change your child's educational placement, or refuses your request for an evaluation or a change in placement.
- **Initiate an evaluation** if you think your child is in need of special education or related services.
- **Informed consent.** *Informed consent* means you understand and agree in writing to the evaluation and educational program decisions for your child. Your consent is voluntary and may be withdrawn at any time.
- **Obtain an independent evaluation** if you disagree with the outcome of the school's evaluation.
- **Request a reevaluation** if you suspect your child's present educational placement is no longer appropriate. The school must *reevaluate* your child at least every 3 years, but your child's educational program must be *reviewed* at least once during each calendar year.
- **Have your child tested in the language he or she knows best.** For example, if your child's primary language is Spanish, this is the language in which he or she must be tested. Also, students who are deaf have the right to an interpreter during the testing.
- **Review all of your child's records.** You may obtain copies of these records, but the school may charge you a reasonable fee for making copies. Only you, as parents, and those persons directly involved in the education of your child will be permitted access to personal records. If you feel that any of the information contained in your child's records is inaccurate or misleading or violates the privacy or other rights of your child, you may request that the information be changed. If the school refuses your request, you then have the right to request a hearing in order to challenge the questionable information in your child's records.
- **Be fully informed by the school of all rights that are provided to you under the law.**
- **Participate in the development of your child's individualized education program (IEP).** The school must make every possible effort to notify you of the IEP meeting and then arrange it at a time and place that is convenient for you. Remember, your child's IEP cannot be implemented without your written consent.
- **Have your child educated in the least restrictive school setting possible.** Every effort should be made to develop an educational program that will provide the greatest amount of contact with nonhandicapped children.
- **Request a due process hearing** to resolve differences with the school that could not be resolved informally.

What are your responsibilities, as a parent, in the special education process?

Parental responsibilities to ensure that a child's rights are being protected are less clearly defined than are parental rights. These responsibilities vary considerably depending on the nature of the child's handicapping condition and other factors. In accepting these responsibilities, some of the following suggestions may be helpful:

- **Develop a partnership with the school or agency.** You are now an important member of the team. Share relevant information about your child's education and development. Your observations and suggestions can be a valuable resource to aid your child's progress.
- **Ask for clarification of any aspect of the program that is unclear to you.** Educational and medical terms can be confusing, so do not hesitate to ask.
- **Make sure you understand the program specified on the IEP before agreeing to it or signing it.** Ask yourself whether or not what is planned corresponds with your knowledge of your child's needs.
- **Make sure your child is included in the regular school activities program.** Do not forget nonacademic areas such as lunch and recess and other areas such as art, music, and physical education.
- **Learn as much as you can about your rights and the rights of your child.** Ask the school to explain these rights as well as the policies and regulations in effect in your district and state before you agree to a special education program for your child.

- **Monitor your child's progress.** If your child is not progressing, discuss it with the teacher and determine whether or not the program should be modified. As a parent, you can initiate changes in your child's educational program.

- **Discuss with the school or agency any problems that may occur with your child's assessment, placement, or educational program.** It is best to try to resolve these problems directly with the agency, school, or district. In some situations, you may be uncertain as to which direction you should take to resolve a problem. Most states have protection and advocacy agencies that can provide you with the guidance you need to pursue your case.

- **Keep records.** There may be many questions and comments about your child that you will want to discuss, as well as meetings and phone conversations you will want to remember. It is easy to forget information useful to your child's development and education that is not written down.

- **Join a parent organization.** In addition to offering the opportunity to share knowledge, experiences, and support, a parent group can be an effective force on behalf of your child. Many times parents find that as a group they have the power to bring about needed changes to strengthen and broaden special services.

As the parent of a child with a handicap, what can you offer the IEP process?

In the final analysis, parents of handicapped children should be involved in the process as much as they want to be and as much as they can be. Varying degrees of involvement are possible. The following are suggestions for ways in which parents can become involved:

- **Before attending an IEP meeting, make a list of things you want your child to learn.** Discuss any differences between your list and the school's or agency's list. Take notes about aspects of your child's behavior that could interfere with the learning process. Describe the methods you have found to be successful in dealing with these behaviors.

- **Bring any information the school or agency may not already have to the IEP meeting.** Examples include copies of medical records, past school records, or test or evaluation results. Remember, reports do not say all there is to say about a child. You can add real-life examples to demonstrate your child's ability in certain areas.

- **Find out what related services are being provided.** Besides your child's teacher, many other specialists and professionals may have contact with your child through provision of related services. Ask each professional to describe the kind of service he or she will be providing and what growth you might expect to see as a result of these services.

- **Ask what you can do at home to support the program.** Many skills the child learns at school can also be used at home. Ask to meet with the teacher when your child is learning a new skill that could be practiced at home.

- **Make sure the goals and objectives on the IEP are specific.** This will ensure that everyone teaching your child is working toward the same goals. Ask questions to make sure that you understand and agree with each of the goals and objectives before signing the IEP.

- **Periodically, ask for a report on your child's progress.** After the meeting is over, your job as parent is not finished. You should follow your child's progress throughout the year.

- **Regard your child's education as a cooperative effort.** If at any point you and the school cannot reach an agreement over your child's educational and developmental needs, ask to have another meeting. This would allow time for you and the school or agency to gather more information and data. If after a second meeting there is still a conflict over your child's program, you should ask for a state mediator or a due process hearing.

What resources are available to help you?

Local and state education agencies have information to help guide you through the special education process. Since there is great variation in the specific criteria and procedures employed by school districts, it is important that you familiarize yourself with the information they provide. You will find your local director of special education and his or her staff helpful in accessing such information and guiding you through the process.

Additional resources are available from national organizations. Some of them will also be able to direct you to local and state chapters that can provide more locally based support. Almost all of the states now have federally supported parent information and training centers. Any of the contacts cited here may be able to help you locate such a center in your state:

The Association for Retarded Citizens of the United States
P.O. Box 6109
2709 Avenue E East
Arlington, TX 76005

Children with Attention Deficit Disorders (CHADD)
Suite 185
1859 North Pine Island Road
Plantation, FL 33322

The Council for Exceptional Children
1920 Association Drive
Reston, VA 22091

Learning Disability Association
5225 Grace Street
Pittsburgh, PA 15236

National Information Center for Children and Youth with Handicaps
P.O. Box 1492
Washington, DC 20013

The Association for Persons with Severe Handicaps (TASH)
7010 Roosevelt Way, NE
Seattle, WA 98115

United Cerebral Palsy Association
7 PEN Plaza
Suite 804
New York, NY 10001

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APPENDIX C
PARENT TRAINING CENTERS

These centers are funded by the Division of Special Education Program (OSEP), U. S. Department of Education, to provide training and information to parents to enable such individuals to participate more effectively with professionals in meeting the educational needs of children with disabilities.

ILLINOIS

Family Resource Center on Disabilities (FRCD)
20 East Jackson Blvd., Room 900
Chicago, IL 60604
312-939-3513
312-939-3519 (TDD/TTY)
800-952-4199
312-939-7297

Designs for Change
6 N. Michigan, Suite 1600
Chicago, IL 60602
312-857-9292

INDIANA

Indiana Resource Center for
Families with Special Needs (IN*SOURCE)
833 E. Northside Blvd., Building 1, Rear
South Bend, IN 46617
219-234-7101 (V/TDD)
800-332-4433 (Indiana only)
219-287-9651 (FAX)

MICHIGAN

Parents are Experts: Parents
Training Parents Project
23077 Greenfield, Rd., Suite 205
Southfield, MI 48075-3744
313-557-5070 (Voice/TDD)
800-221-9105
517-485-4145 (FAX)

Citizens Alliance to Uphold Special
Education (CAUSE)
313 So. Washington Sq. Suite 040
Lansing, MI 48933
517-485-4084 (Voice/TDD)
800-221-9105
517-485-4145 (FAX)

MINNESOTA

PACER Center, Inc.
4826 Chicago Avenue South
Minneapolis, MN 55417
612-827-2966 (V/TDD)
800-53P-ACER (parents only)
612-827-3065 (FAX)

OHIO

Child Advocacy Center
1821 Summit Road, Suite 303
Cincinnati, OH 45237
513-821-2400
513-821-2442 (FAX)

Ohio Coalition for the Education of Handicapped Children (OCEHC)
1299 Campbell Road, Suite B
Marion, OH 43302
614-382-5452 (Voice/TDD)
800-374-2806

Training Center
933 HIgh St., Suite 106
Worthington, OH 43085
614-431-1307 (V/TDD)

WISCONSIN

Parent Education Project of WI, Inc. (PEP-WI)
2001 West Vliet St.
Milwaukee, WI 53205
414-937-8380
800-231-8382
414-933-6077 (FAX)

APPENDIX D
A GOOD ADVOCATE

A Good Advocate . . .

. . . **gathers information.** Know your rights! Read records!

. . . **sets goals and objectives.** Be prepared! Have a plan. Know what you want to get out of each meeting.

. . . **is assertive, not antagonistic.** Don't lose your cool!

. . . **is a good listener.** Listen carefully! So much good information can be collected at a meeting. Take notes for further reference.

. . . **doesn't assume anything.** Don't be afraid to ask questions!

. . . **isn't controlled by the clock.** Meetings can always be rescheduled. If you have issues you know will need more time, notify your district. Don't let the clock pressure you into signing something you don't agree with, or you don't understand.

. . . **cooperates.** Remember, you can cooperate without agreeing. Even though you may not agree with a placement or program, look at it! You can't fight something you know nothing about.

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APPENDIX E
ADVOCACY BEFORE ANY MEETING

ADVOCACY

Before any meeting.....

SET GOALS - Be proactive instead of reactive!

Whether you're making a phone call, visiting a teacher, or going to a staffing it's important to have a goal for what you want to accomplish. Don't wait for the roof to cave in before you act. A good advocate sets a goal and considers all the barriers, and problems that can arise.

GATHER INFORMATION - You can never be too prepared!

Useschool records, your child's daily work, outside evaluations, and all information available.

DEVELOP A STATEGY - Don't generalize, know exactly what you want!

Saying "I want my child fully included," means nothing. Be specific! Consider all options! What will you do if they offer you pull - out speech and language services? Adaptive PE.? What needs to happen for your child to be included? Does your child need additional skills? Whose attitudes will you need to change? How will you do that? Consider all barriers and brain storm solutions. Remember it may take you time and a series of meetings, to reach your goal.

At a meeting.....

BUILD RELATIONSHIPS - Don't come in with an attitude!

Negative actions and attitudes, make people defensive. If people are attacked or feel threatened, they may resist your suggestions no matter how great they are. The time before a meeting starts can set the tone for how well people will listen to one another and work together later.

GET AN UPDATE - Don't ever assume you know everything!

No matter how prepared you are, always clarify the purpose of the meeting and make sure that you know exactly what the issues are. Information can get twisted and tangled, and sometimes critical issues have been barried.

LISTEN - Listen to understand!

Listening is , if not the most, one of the most important steps, yet most people don't listen well. If you don't listen carefully, you may miss key factors, and ideas. The information that is shared may impact your strategy. Be careful not to react to negative feedback. These comments are better off lost, then attacked.

ASK QUESTIONS - You can't know everything!

Asking questions has nothing to do with intelligence. No matter how much material you read or how up to date you feel you are, there's no one that knows everything.

ANALYZE - Reevaluate your strategy!

How does this information effect my strategy? Will my strategy need to change? What is reasonable? What can I really get? Are there any more questions to ask? What steps do I need to take next ?

MAKE SUGGESTIONS - Facilitate when necessary!

Demands aren't received well. At most meetings, plans aren't working well, and many folks are frustrated to begin with. One suggestion can be the catalyst to getting everyone in the problem solving mode! Remember, even though you may be up-to-date on the latest laws or know where that appropriate resource is, don't assume everyone else is familiar with it. Facilitate information and options when necessary. Don't make it just their job!

WHEN DISAGREEMENTS OCCUR - Be assertive - not antagonistic

Disagreements are normal, but remember you will still have to work with these folks, so choose your fights carefully. Don't make your fights personal! Remember, you can disagree and still be cooperative. Know your rights! Don't get caught up in a situation where what you're proposing, the school district is not responsible for. If you're not sure of your next steps, ajourn the meeting. Reevaluate the meeting, and develop your next stategy.

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APPENDIX F
TIPS FOR DEVELOPING EFFECTIVE STRATEGIES

- **Gather Information**
  Listen carefully, get records if necessary, make sure you have **all** of the necessary information.

- **Ask Questions**
  Don't be afraid to ask additional questions. Most people don't know what information is important, and in their frustration may forget to give you critical details.

- **Define the Problem**
  In most cases people will give you too much information. Make sure you have a clear picture of the problem and clarify it with them .

- **Stay Child Focused**
  Getting rid of a teacher is a long process, and doesn't help a child who is failing reading. Keep the conversation child focused. Getting mixed up in "get even" activities is a time waster and doesn't benefit children.

- **Work to Solve Problems, not Create Them**
  Even though filing for Due Process will help solve many problems, take the quickest and easiest route when problem solving any issue. Work with the parents on ways they can solve the problem that will promote a working relationship between the parent and district. Use complaints and Due Process as a last resort.

- **Be Honest**
  If you don't know how to solve a problem, be honest and if possible refer the parent to another group or agency. If what their asking for is unrealistic, or if they've misinterpreted the law, talk the issue through, so that you can help them redefine the issue or problem solve and develop other solutions.

- **Be Prepared**
  The initial strategy you create may have to be redefined on several occasions, as additional data is collected, or as situations change. Be prepared to make adjustments. Solving some problems may take many phone calls and meetings to resolve.

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APPENDIX G
ADVOCACY-PROBLEM PERSONALITIES

The Policeman Personality

From the time the staffing begins, this person makes sure that everyone knows that they are up-to-date on all laws. During the staffing they spend most of the time looking for legal technicalities. Since most of their energies are spent on "catching the district" the needs of the child take a backseat.

The Lawyer Personality

The lawyer personality is also caught up in his legal rights, only his focus is on "taking the "district to court." When ever there's a problem, his basic solution is to take the district to Due Process. Because he uses this threat so often, no one takes his threats or even his good ideas seriously.

The Dictator Personality

The dictator is always well prepared, but has no desire to work as part of any team. She enters every meeting angry and takes control by demanding things for her child. She begins most sentences with "You will," and "I want." People hate working and even communicating with her. Because of the way she acts, teachers and therapists don't contact her with problems, and they are eager to just move her child along, so they don't have to deal with her anymore.

The Minnie Mouse Personality

Minnie Mouse knows her rights, shows up at every meeting, but never asks a question or disagrees with anyone. Even though she knows her child's program is inappropriate, she goes along with things for fear someone will "take it out on her child." Everyone in the district likes her, and describes her as one of the "easiest parents to deal with."

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STATE UPDATES

THANKS FOR THE BEST NEEDS ASSESSMENT RETURN EVER. THE RESULTS WILL HELP US WRITE OUR NEXT PROPOSAL AND GUIDE OUR PLANNING THIS SPRING. WE'LL SHARE THE RESULTS SOON.

Illinois

A draft copy of the Illinois Interagency Agreement was produced by a committee which met on February 15, 1994 in the Regional Office. The committee is composed of the RAP Project Coordinator, Region V staff, Illinois Head Start Association members, and staff from the Illinois State Board of Education. The draft agreement covers collaborative services to be delivered to young children and their families. A review meeting will be held in Matteson, IL on May 4, 1994 to solicit ideas for implementation from the Head Start and Early Childhood communities.

Gay Chisum, a consultant from Chicago who has worked with Dr. Ira Chasnoff in the area of perinatal abuse and research, presented a half-day workshop in Mt. Vernon to thirty-one teachers and coordinators from southern and central Illinois. The workshop features slides, lecture and intervention strategies on the topic of Fetal Alcohol Syndrome for the Head Start classroom. This workshop was the final in a series of Fetal Alcohol Syndrome workshops in Illinois and Indiana presented by Ms. Gay Chisum.

The Illinois Retreat has been planned for Directors and Disabilities Coordinators at the Robert Allerton Conference Center in Monticello for April 25-26, 1994. The topic for the two half day sessions will be skill building for writing interagency agreements and how to more effectively collaborate with public schools. Dr. Linda Kunesh from the North Central Regional Education Lab and Pam Reising from the Illinois State Board of Education are actively involved in the two day retreat.

Head Start Disabilities Coordinators have been invited to participate in Inclusion Leadership Training for Child Care. The training will assist all child care facilities in Illinois to include children with disabilities in an integrated setting. The training will take place April 11-12 in Champaign, April 28-29 in Mt. Vernon and May 10-11 in Chicago.

The Illinois Staff Development Committee will meet on April 5, 1994 to discuss how to best share and coordinate training in Illinois. The Project Coordinator will share the results of the Head Start Needs Assessments from Illinois. Illinois is fortunate to have several training projects that share resources and materials.

Indiana

The Indiana Program Support Specialist presented a three-hour session in Indianapolis for forty-two coordinators and teachers from Indiana Head Start programs on February 4, 1994. The topic was "Overview of Exceptional Children" and featured lecture, small

group discussion and simulations of various disabilities. The main objectives of the workshop included: a) to learn basic information concerning ten disabilities and b) to become aware of the unique frustrations and feelings that may accompany a specific disability.

Dr. Barbara Jean Reid, of the University of Wisconsin, presented a full-day session entitled "Emotional Issues with Children." This workshop featured lecture and hands-on intervention strategies to a limited group of Disabilities and Education Coordinators and teachers from Indiana and Illinois. It took place on the campus of Huntington College, Huntington, Indiana on March 25, 1994.

Plans are being made for the annual Spring Retreat at Brown County State Park, May 5-6, 1994. The topic will be "Writing Disability Plans."

Michigan

The Joint Conference for Early Childhood Educators February 2-4, 1994 was attended by over 850 persons from all areas of early childhood. The evaluations were overwhelming positive. Participants expressed a high level of satisfaction with the disability track which featured sessions on health, orthopedic, emotional, speech and language, hearing, and vision impairments as well as ADD, autism, and parent involvement. A new feature of the conference was an on-going filmfest. Dr. James Willis, Dickinson-Iron Head Start Director, was awarded the prestigious Jane Scandary award for exceptional efforts in early childhood special education. Congratulations, Jim!

EMPRISE DESIGNS Technical Assistance Support Center State Lead Consultant, Ivan Mecks, and Lead Health Consultant, Meredith Mentzer, have announced three mandatory trainings: The first is in the area of fiscal management aimed at directors, fiscal management aimed at directors, fiscal support, and Policy Council chairpersons. The second is new staff training aimed at all new staff. The third training is Phase III Management training. The emphasis will be on managing change and expansion. Emprise will also provide T/TA to programs in efforts to meet CDA requirements by September, 1994.

The Great Lakes RAP three part series, Managing Difficult Behavior, presented by consultant Donna Rhodes Ollerman received more registration requests than could be honored due to limited space. We apologize to many people who had to be turned away. A repeat of the series will be considered for next year.

The second in a series of training events for Michigan Disabilities Coordinators occurred March 18, 1994 at Greenville's historic Winter Inn. The focus of this day long training was Strategies for Obtaining Written Interagency Agreements. Four coordinators representing large, small, urban, and rural programs shared their experiences in obtaining agreements. A highlight of the event was A Special Educator's Perspective presented by Dr. James Nuttall from the Office of Special Education, Michigan Department of Education.

Approximately $35 million will come to Michigan over the next five years under the new capped entitlement created by the Family Preservation and Support Services Act. The federal act requires that states develop plans for the use of new family preservation funds, and that they consult with private, non-profit and community based organizations in developing those plans. For more information, contact Cynthia H. Wilbanks at Michigan's Children (517) 349-8669.

Minnesota

May 10-11, 1994. Minnesota Head Start Association Meeting. Kelly Inn, St. Cloud, Minnesota.

September 29-30, 1994. Minnesota Head Start State Training Conference. Kahler Hotel, Rochester, Minnesota.

Don't forget, the Minnesota Head Start programs will be hosting the Region V Head Start Conference in the Twin Cities in the autumn of 1995.

Ohio

New officers of the Ohio Head Start Association, Inc. are: Jerry Scott, President; Mary Burns, Vice-President; and Lois Reed, Treasurer. Bi-monthly OHSAI Meetings are held during the months of October, December, February, April and June. Most meetings are two days and are held in Columbus, OH. The exception is the June Retreat which is scheduled June 6-10 this year and will be held at King's Island in Mason, OH.

The Interagency Task Force Meeting between the Ohio Department of Education, Early Childhood Division and the Ohio Head Start Association, Inc. was held on March 15, 1994 in Columbus, OH. Approximately fifteen participants were involved in an all-day meeting to begin the updating of the state interagency agreement. A facilitator was present from NEC*TAS. Public school preschools are required to follow Head Start regulations as of September 1, 1994 and this meeting initiated the collaborative effort.

Training for Disabilities Coordinators, Health Coordinators and other Head Start staff will be held during the regularly-scheduled Ohio Head Start Association Meeting -- April 5-6, 1994. Sessions will include: (1) A discussion of regulations for public preschool children with disabilities by an Early Childhood Coordinator from the Dayton Special Education Regional Resource Center (SERRC); (2) A workshop on vision screening; (3) A workshop on blood pathogens and blood pathogen policy; and (4) A discussion of anticipated changes in the SEA agreement and how this will assist local Head Start programs in working collaboratively with the LEA.

The Ohio RAP Program Support Specialist can be reached by contacting the Ohio Head Start Association office, 66 Marco Lane, Dayton, OH 45458 (513-435-1113).

Wisconsin

Assembly Bill 893, an amendment to Section 115.85, Wisconsin Statutes, is being considered by the Assembly and will soon come up for a vote. This amendment would enable interagency collaboration in the evaluation of children. It would permit a school board, Cooperative Educational Service Agency and county handicapped children's board to enter into agreement with a Birth To Three program which would allow school district employees to participate in the performance of Birth to Three evaluations and IFSP development under Part H. Part B of the proposal would allow schools to enter into agreements to utilize staff from Birth To Three, Head Start and Tribal Schools a s team members on the school evaluation. This would increase the input of these sending agencies to provide the school with more flexibility in the staff utilized in the M-team.

April 12, 1994. Disabilities Preconference Day sponsored by the National Resource Access Project (RAP) Network. Louisville, Kentucky. Flyers will be sent notifying Disabilities Coordinators of this event. Call your RAP for more information.

April 12-15, 1994. National Head Start Association Conference. Louisville, Kentucky.

April 19, 1994. RAP Teleconference for Minnesota, Michigan, and Wisconsin Disabilities Coordinators. Subject to be announced. A flyer will be mailed to all Disabilities Coordinators.

rap
Great Lakes Resource Access Project

Great Lakes Resource Access Project
Department of Special Education
University of Illinois at Urbana-Champaign
240 Colonel Wolfe School
403 E. Healey
Champaign, Illinois 61820

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